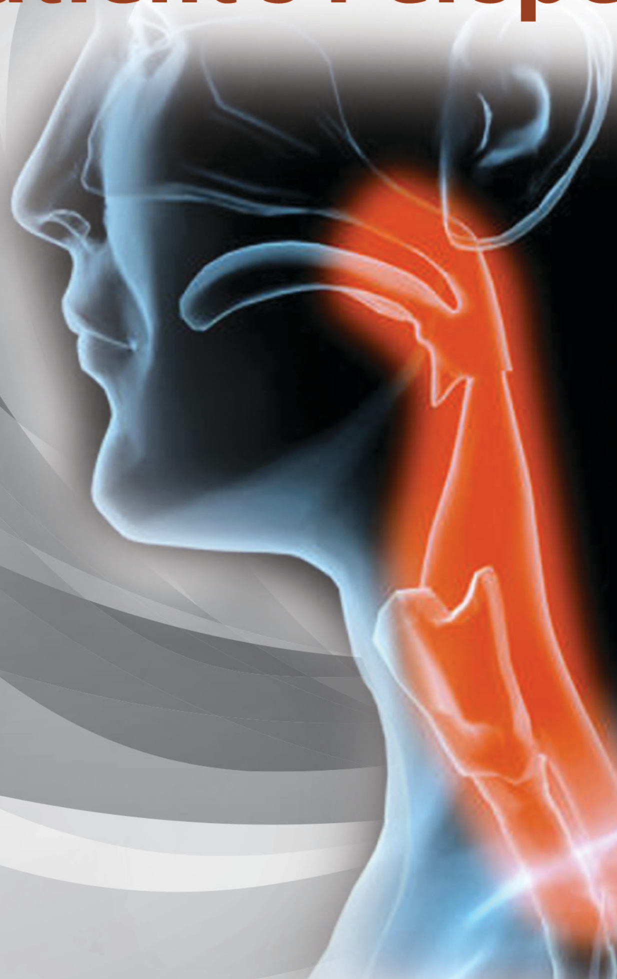
DBS4PD.org
an affiliate of The Parkinson Alliance
Improving the Quality of Life in the Parkinson's Community

Fall 2017

Swallowing and Parkinson's Disease: The Patient's Perspective



INTRODUCTION

People with Parkinson's disease (PWP) experience numerous symptoms beyond the cardinal signs of Parkinson's disease (PD): slowness of movement, balance problems, tremor, and rigidity. One such symptom is swallowing difficulty, which is also known as dysphagia. Swallowing dysfunction can lead to isolation, emotional disturbance, additional medical problems, and even mortality[1]. The incidence of swallowing dysfunction in PD ranges from 30 to 52%[2], though some research has indicated that up to 90 to 100% of individuals with advanced disease stages of PD develop swallowing dysfunction[3,4]. Frequency data for swallowing dysfunction vary widely according to underlying classification, measuring method, and disease stage[4]. Notably, swallowing difficulty can lead to aspiration (entry of foreign objects into one's airways), which can result in choking or pneumonia, the latter being a leading cause of death for individuals with PD[5]. Aspiration, or silent aspiration (aspirating without a cough), may also appear before individuals with PD recognize difficulty swallowing[2], increasing the risk for medical complications. Medical complications can include airway obstruction/choking, respiratory distress, pneumonia, weight loss, and dehydration.

Swallowing difficulties can interfere with quality of life[2,6,7]. Swallowing difficulties have been linked to social withdrawal[8,9,10], decreased self-esteem[8,9,10], and increased mealtime anxiety[8,10]. Swallowing related quality of life was significantly reduced with increased swallowing deficits, and domains of feeling like a burden, social function (i.e., reduced time with others), and mental health were most detrimentally impacted by swallowing difficulties[1].

Treatments for swallowing difficulties may take many forms. Treatments have included speech therapy rehabilitation with a focus on swallowing; postural and airway protective maneuvers, pharmacological interventions, food modification, neuromuscular electrical stimulation, and surgical treatments[11,12]. A lack of sufficient evidence for some treatments for swallowing difficulties has been noted. Furthermore, cognitive-behavioral therapy (psychotherapy) may also be a helpful treatment to assist individuals with coping with the life changes that result from swallowing difficulties[13].

OBJECTIVES

1. To identify relationships between age, PD duration, and severity of swallowing difficulty from the patient's perspective.
2. To understand the patient's perspective about assessment and treatment related to swallowing function.
3. To understand the impact of swallowing on quality of life.

METHODS

- Participants were recruited from prior survey participation that was conducted by The Parkinson Alliance (PA), announcements at PD support groups, announcements in medical clinics, The PA website, or a DBS-focused affiliate website to The PA (DBS4PD.org).
- There were 1,390 individuals who participated in this survey, including 377 participants with PD who underwent **DBS** and 1,013 individuals with PD without DBS (**Non-DBS group**; see Table 1 for demographics and clinical features).
- Participants represented 50 states, with California (14%), Arizona (10%), Texas (12%), Florida (9%), New Jersey (9%), New York (8%), Pennsylvania (4%), Colorado (4%), Minnesota (3%), and Michigan (3%) being the top 10 states with the most participants. Geographical distribution was comparable between groups. There were 16 international participants.

- For participants in this survey, approximately 85% completed their survey independently, whereas, 15% of participants required assistance.

Measures:

- The questionnaires used in this survey included: the Demographic Questionnaire, an instrument created by the Parkinson Alliance entitled "Parkinson Alliance Swallowing Scale," and additional questions related to swallowing and quality of life.

The Demographic Questionnaire:

- The self-report questionnaire inquired about basic demographic information (e.g., gender, marital status, education) as well as pertinent clinical information pertaining to swallowing and quality of life.

Parkinson Alliance Swallowing Scale (PASS):

- The PASS is a 23-item, self-report questionnaire with three domains: Chewing, Swallowing, and Other. The "Chewing" domain had 2 items, the "Swallowing" domain had 15 items, and the "Other" domain had 6 items. The other domain included questions related to swallowing such as, "Do you experience heartburn or reflux?", Do you experience difficulty breathing during a meal?", "Immediately following a meal, do you experience coughing?" The participants rated their perceived swallowing difficulties on a 5-point Likert scale: Never, Rarely (less than once per month), Frequently (several times per month), Quite Often (multiple times per week), Always (daily; during every meal), ratings being measured as 0 (Never) to 4 (Always). In each domain, the values were added together to create a total score for Chewing, Swallowing, and Other. Higher scores mean greater difficulties with swallowing. A total score was also calculated by using the sum of all of the items within each domain.

Comparisons based on age and disease duration groups:

- The results will be presented using the entire sample for individuals who completed the survey (N=1,390) and in the context of groups matched on age and disease duration.
  - Age: Age groups were divided into a **Younger PD group** (ages 50-69 years of age) and an **Older PD group** (ages 70+ years)
  - Disease Duration: To better illustrate the impact of disease duration on variables related to swallowing in individuals with PD, this survey divided disease duration groups into **Early Stage PD (<6 years), Early Advanced Stage PD (6-10 years),** and **Late Advanced Stage PD (11+ years)**.

Factors to consider when interpreting the results:

- This study used a survey-based methodology. Generalizability of the results may be limited. Sample sizes noted in the sections below may vary somewhat within specific groups (e.g., younger, older, early, advanced, etc.), since some individuals may not have responded to a specific question.

RESULTS

The summary of the demographic information and clinical characteristics of the participants in this study can be found in Table 1. The **Non-DBS group's** age was comparable to the **DBS group (average: 72 versus 68 years, respectively).** By contrast, the **DBS group** had a younger average age of PD diagnosis **(52 years)** than the **Non-DBS group (64 years)** and a longer duration of PD (see Table 1). Gender (male greater than female), marital status (the majority being married), race (the majority being White/Caucasian), and education (the majority having higher education) were comparable between these two groups.

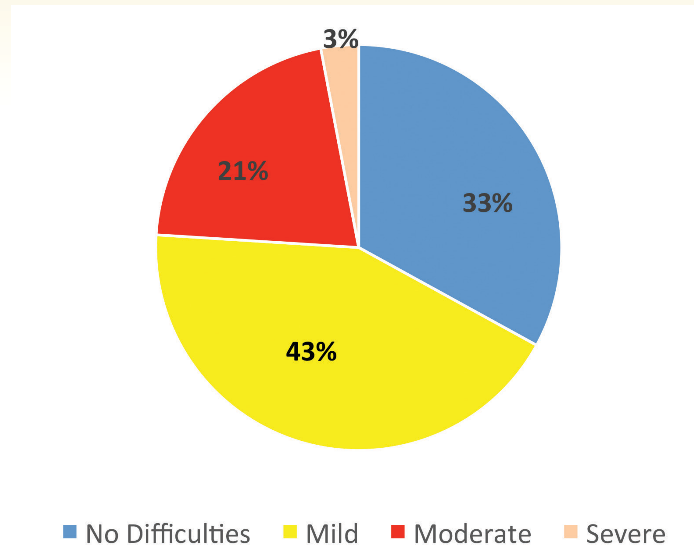
Table 1. Demographics and Clinical Features of the Sample		
	DBS (*n* =377)	**Non-DBS (*n* =1,013)**
Average Age in Years (range)*	68 (44-89)	72 (43-105)
Duration of PD in Years (range)*	16 (0-38)	8 (0-41)
Average Age of PD Diagnosis (range)*	52 (31-76)	64 (32-92)
Average Age at Time of DBS in Years (range)	62 (36-84)	n/a
Average Duration since DBS in Years (range)	6 (0-25)	n/a
Target: STN	50%	n/a
GPi	7%	n/a
Not Sure	43%	n/a
Male	56%	54%
Female	44%	46%
Married	78%	76%
Lives Alone	12%	17%
Race		
Caucasian	94%	94%
Latino/Hispanic	3%	3%
African American	1%	<1%
Asian	1%	2%
American Indian	<1%	<1%
Native Hawaiian or Pacific Islander	<1%	<1%
Other	n/a	n/a
Education		
<12 years	2%	4%
High School	8%	7%
Some College or Associate's Degree	27%	23%
College	31%	29%
Graduate/Advanced Degree	32%	37%

* Clinically significant difference between groups
n/a = not applicable

PERCEIVED PERCEIVED SWALLOWING DIFFICULTIES

- 67% of the participants reported that they experience swallowing difficulties, with the majority (43%) of participants reporting mild difficulties with swallowing and 24% reporting moderate to severe difficulties (see Figure 1)
- When asked about level of concern about his/her swallowing difficulties, 10% were "quite a bit" to "extremely" concerned, while 22% were moderately concerned and 35% were "a little bit" concerned
- 31% of the participants indicated that others had concerns about his/her swallowing

Figure 1. Participants experiencing swallowing difficulties (N=1,385):



- 87% of the participants reported that they do not have a modified diet
  - 9% reported having modified food texture (eating more soft foods; pureed foods)
  - 2% reported having modified food and liquids
  - 1% reported modified thin liquids only
  - <1% reported use of a feeding tube
- 19% of the participants reported that they require some assistance with eating:
  - 14% reported "a little bit" of assistance
  - 3% reported "moderate"
  - 2% reported "quite a bit" of assistance
- Type of assistance needed:
  - 25% reported that they need assistance eating solid foods with a knife and fork
  - 1% reported that assistance was required when eating soft foods such as bananas or soft desserts
  - 1% reported that they need assistance with eating pureed food
  - 2% reported that assistance was needed when drinking liquids
- Frequency of requiring assistance:
  - Every meal: 7%
  - Some meals: 33%
- 12% of the participants reported that they consume foods and/or beverages that they are not supposed to eat or drink
- Modified Utensils:
  - 6% reported use of modified utensils to assist with eating
  - 18% of those who use modified utensils reported that they find the modified utensils helpful

- When asked about difficulty swallowing pills:
    - 52% reported no difficulties
    - 41% reported "a little difficulty"
    - 4% reported that swallowing pills is quite challenging every day
    - 3% reported that they require use of thickening substances to take pills (i.e., apple sauce)
- 35% of the participants reported that they try to hide or minimize their swallowing difficulty
- Swallowing difficulties interfered with dining or eating with others for many participants:
    - 23% reported that they eat meals in the presence of others, but they have to pay attention to swallowing
    - 10% prefer to eat in the presence of familiar people in familiar places
    - 2% only eat at home and in the presence of familiar people
    - <1% only eat at home with the assistance of a care provider
    - 64% reported no difficulties eating with others
- Difficulty swallowing saliva was reported to limit socialization:
    - "A little bit" for 21% of the participants
    - "Moderately" for 6% of the participants
    - "Quite a bit" for 3% of the participants
    - "Extremely" for <1% of the participants
- 12% of the participants reported having had a respiratory infection
- 12% of the participants were hospitalized for a respiratory infection

PARKINSON ALLIANCE SWALLOWING SURVEY (PASS; N=1,390):

- As seen in **Figure 1**, the most frequently reported swallowing related symptoms included wiping one's nose when eating or drinking, sneezing while eating, experiencing too much saliva in one's mouth when not eating, heartburn or acid reflux, difficulty chewing solid food that requires a lot of chewing.
    - These symptoms were reported by 25% to 39% of the participants and were experienced as occurring frequently (occurring several times per month) to always (daily or during every meal).
- The least frequently reported symptoms included difficulty swallowing pureed food (note, only 1% of participants reported eating pureed food), pain when swallowing, difficulty breathing during meals, choking while swallowing thick liquids, and difficulty chewing solid food with "a little bit" of chewing.
    - These symptoms were reported by 1% to 9% of the participants and were experienced as occurring frequently (occurring several times per month) to always (daily or during every meal).
- **Table 2** highlights the frequency of symptoms related to swallowing difficulties across age and disease duration groups.
    - For participants in this study, many symptoms related to swallowing are reported in greater frequency as age and disease duration progress.
        - Notably, for these participants, generally, as age and disease duration increased, the increase in severity of swallowing difficulties across groups went from "Never/Rarely" to "Frequent/Quite Often" (Several times per month/multiple times per week).

- When looking at the subdomains of the PASS (*symptoms for Chewing, Swallowing, and Other (i.e., heartburn; coughing; sneezing; wiping one's nose during a meal), the* ***Advanced Disease Duration group (11+ years)*** *for* ***both Younger and Older participants*** *reported symptoms in greater frequency as compared to the* ***Early Disease Duration*** *and* ***Advanced 6-10 Years Disease Duration groups****.*
- **Older individuals** (70+ years of age) with **greater disease duration** (i.e., 11+ years of PD) reported the following symptoms in GREATER frequency (though generally modest on some items) when compared to **Younger** and **earlier disease duration groups :** excess saliva when not eating or drinking, coughing when swallowing foods or liquids, choking when eating solid foods, dribbling of food or liquids when eating, food residue getting stuck in one's mouth after eating, difficulty chewing solid food, wiping nose when eating or drinking, and sneezing when eating or drinking.
- **There was NOT a significant difference between age and disease duration groups for the following symptoms:** coughing after finishing meals, changes in voice following a meal, difficulty breathing during meals, heartburn or reflux, coughing or difficulties breathing as a result of saliva entering one's windpipe, pain when swallowing, difficulty swallowing pureed food.

Figure 2. Symptoms related to swallowing difficulties: Reported as Occurring "Frequently" to "Always" (N=1,390)

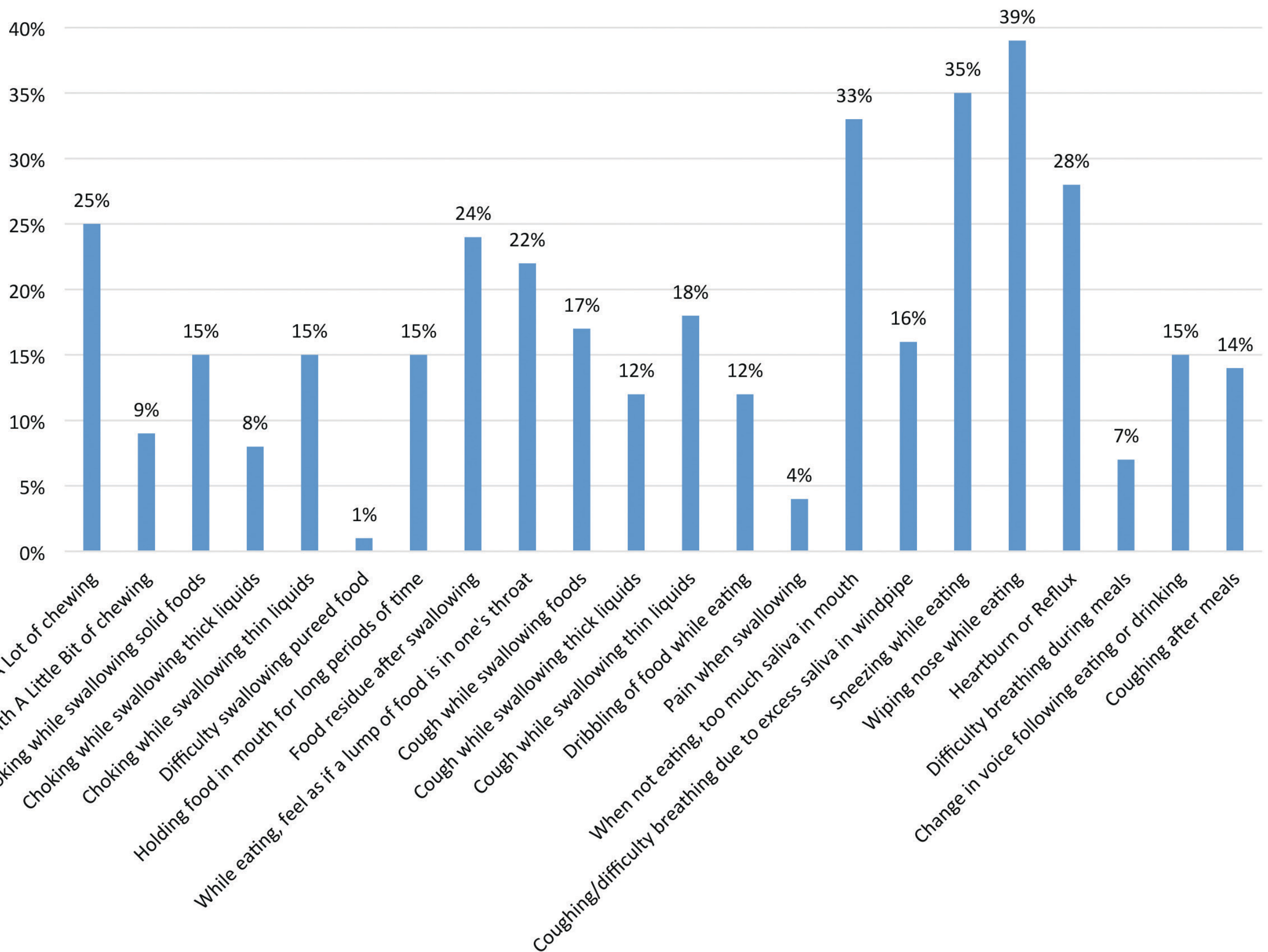


Table 2. Participants Reporting Swallowing Difficulties Across Age and Disease Duration Cohorts:						
	Early PD Group		Advanced PD Group			
	(<6 years duration)		6-10 years duration		11+ years duration	
Swallowing Dificulties	**Younger (50-69) (n =1348-1379)**	**Older (70+) (n =205-210)**	**Younger (50-69) (n =151-156)**	**Older (70+) (n = 232-240)**	**Younger (50-69) (n =206-209)**	**Older (70+) (n =291-301)**
CHEWING ITEMS:						
Do you experience difficulty chewing solid food that requires a lot of chewing (i.e., meat)						
Never/Rarely	75%	83%	74%	79%	69%	69%
Frequent and Quite Often	22%	14%	22%	20%	27%	29%
Always	3%	3%	4%	1%	3%	5%
Do you experience difficulty chewing solid food that requires a little bit of chewing (i.e., pasta or banana)						
Never/Rarely	91%	95%	94%	94%	89%	85%
Frequent and Quite Often	8%	5%	6%	6%	11%	15%
Always	<1%	0%	1%	0%	0%	1%
SWALLOWING ITEMS:						
Do you choke while swallowing solid foods						
Never/Rarely	85%	91%	85%	89%	81%	78%
Frequent and Quite Often	14%	9%	15%	11%	18%	22%
Always	<1%	0%	1%	0%	1%	1%
Do you experience difficulty swallowing thin liquids (i.e., water, tea, or coffee)						
Never/Rarely	85%	94%	85%	88%	77%	81%
Frequent and Quite Often	13%	5%	13%	11%	22%	15%
Always	2%	1%	2%	1%	2%	4%
Do you have difficulty swallowing pureed food						
Never/Rarely	97%	99%	96%	97%	96%	95%
Frequent and Quite Often	3%	2%	4%	3%	4%	5%
Always	<1%	0%	0%	0%	0%	>1%
Do you hold food/liquid in your mouth for a long period before you swallow						
Never/Rarely	85%	92%	87%	89%	80%	76%
Frequent and Quite Often	14%	6%	12%	12%	19%	22%
Always	1%	1%	1%	0%	1%	3%
Are there any food residues in your mouth, cheeks, under your tongue, or stuck to the roof of your mouth after swallowing						
Never/Rarely	76%	83%	83%	80%	71%	66%
Frequent and Quite Often	21%	15%	15%	20%	24%	30%
Always	3%	1%	3%	1%	5%	4%
While eating, do you feel as if a lump of food is stuck in your throat						
Never/Rarely	78%	83%	81%	82%	71%	76%
Frequent and Quite Often	21%	16%	20%	18%	27%	22%
Always	1%	1%	0%	0%	2%	2%
Do you choke while swallowing thick liquids						
Never/Rarely	92%	98%	91%	93%	90%	88%
Frequent and Quite Often	8%	2%	8%	7%	10%	12%
Always	<1%	0%	1%	<1%	1%	1%

Do you choke while swallowing thin liquids						
Never/Rarely	85%	93%	85%	88%	78%	80%
Frequent and Quite Often	14%	6%	14%	11%	22%	18%
Always	1%	1%	1%	<1%	2%	3%
Do you cough while swallowing solid foods						
Never/Rarely	83%	90%	83%	90%	75%	78%
Frequent and Quite Often	16%	10%	17%	10%	23%	22%
Always	1%	0%	1%	0%	2%	1%
Do you cough while swallowing thick liquids						
Never/Rarely	88%	93%	87%	91%	83%	83%
Frequent and Quite Often	11%	7%	14%	9%	16%	16%
Always	<1%	0%	0%	0%	1%	1%
Do you cough while swallowing thin liquids						
Never/Rarely	82%	92%	80%	86%	69%	77%
Frequent and Quite Often	17%	8%	19%	14%	28%	20%
Always	2%	1%	1%	<1%	3%	3%
Does chewed up food or liquid dribble from your mouth when you are eating						
Never/Rarely	88%	91%	88%	89%	85%	81%
Frequent and Quite Often	12%	7%	12%	10%	14%	18%
Always	1%	1%	0%	1%	1%	1%
Do you experience pain when you swallow						
Never/Rarely	96%	98%	95%	97%	96%	95%
Frequent and Quite Often	4%	2%	5%	3%	4%	5%
Always	<1%	0%	0%	0%	0%	0%
When you are NOT eating, do you feel you have too much saliva in your mouth						
Never/Rarely	67%	71%	68%	69%	64%	57%
Frequent and Quite Often	27%	23%	26%	25%	29%	33%
Always	7%	6%	5%	7%	8%	10%
When you are NOT eating, do you experience coughing or difficulty breathing as a result of saliva entering your windpipe						
Never/Rarely	84%	85%	85%	90%	76%	81%
Frequent and Quite Often	14%	14%	12%	8%	22%	17%
Always	2%	1%	3%	2%	3%	2%
OTHER ITEMS:						
To what extent do you experience sneezing or a runny nose when you eat or drink						
Never/Rarely	65%	66%	65%	62%	68%	59%
Frequent and Quite Often	30%	32%	33%	31%	29%	33%
Always	5%	2%	3%	7%	3%	8%
How often do you wipe your nose when you are eating or drinking						
Never/Rarely	61%	60%	59%	56%	66%	53%
Frequent and Quite Often	34%	38%	34%	38%	31%	38%
Always	6%	1%	7%	6%	3%	10%
Do you experience heartburn or reflux						
Never/Rarely	72%	81%	69%	70%	69%	72%
Frequent and Quite Often	26%	20%	29%	29%	28%	25%
Always	2%	0%	2%	1%	3%	3%

Do you experience difficulty breathing during meals						
Never/Rarely	93%	97%	93%	94%	87%	93%
Frequent and Quite Often	7%	3%	7%	6%	13%	7%
Always	<1%	0%	0%	0%	1%	0%
Immediately after eating or drinking, do you experience a change in your voice (i.e., hoarseness or wetness)						
Never/Rarely	85%	92%	86%	84%	81%	84%
Frequent and Quite Often	14%	7%	14%	14%	18%	16%
Always	1%	1%	0%	2%	1%	1%
After finishing your meals, do you experience coughing						
Never/Rarely	86%	90%	84%	90%	82%	84%
Frequent and Quite Often	13%	9%	15%	9%	18%	15%
Always	1%	1%	1%	1%	1%	1%

EVALUATION AND TREATMENT FOR SWALLOWING DIFFICULTIES:

- 34% of the participants have had a swallowing evaluation
- 37% reported that they ask about the expertise of the clinician who is evaluating swallowing

Barium Swallow Test (N=1,364):

- A barium swallow test uses barium sulfate (metallic compound) that shows up on X-rays and looks at the esophagus how the food travels from the food pipe to the stomach
- A modified barium swallow looks at the mouth and throat and assesses for aspiration and need for food modification
  - 48% of the participants have heard of a Barium Swallow Test
  - 24% of the participants have had a Barium Swallow Test
  - 23% have heard about a modified Barium Swallow Test
  - 13% have had a modified Barium Swallow Test

Fiberoptic Endoscopic Evaluation of Swallowing (FEES) (N=1,363):

- FEES is a procedure to assess areas surrounding the voice box and opening of the esophagus, through the use of a small flexible telescope that is inserted through the nose to access the throat
  - 19% of the participants have heard of FEES Test
  - 8% reported that they have had a FEES Test

Number of swallowing tests that a participant has had (N=1,209):

- 1 test: 19%
- 2 tests: 10%
- 3-5 tests: 5%
- More than 5 tests: 1%
- Not applicable: 65%

Frequency of swallowing tests, if evaluated more than once (N=266):

- Every 6 months: 1%
- Every year: 3%
- Every 2 years: 4%
- Other

TREATMENT:

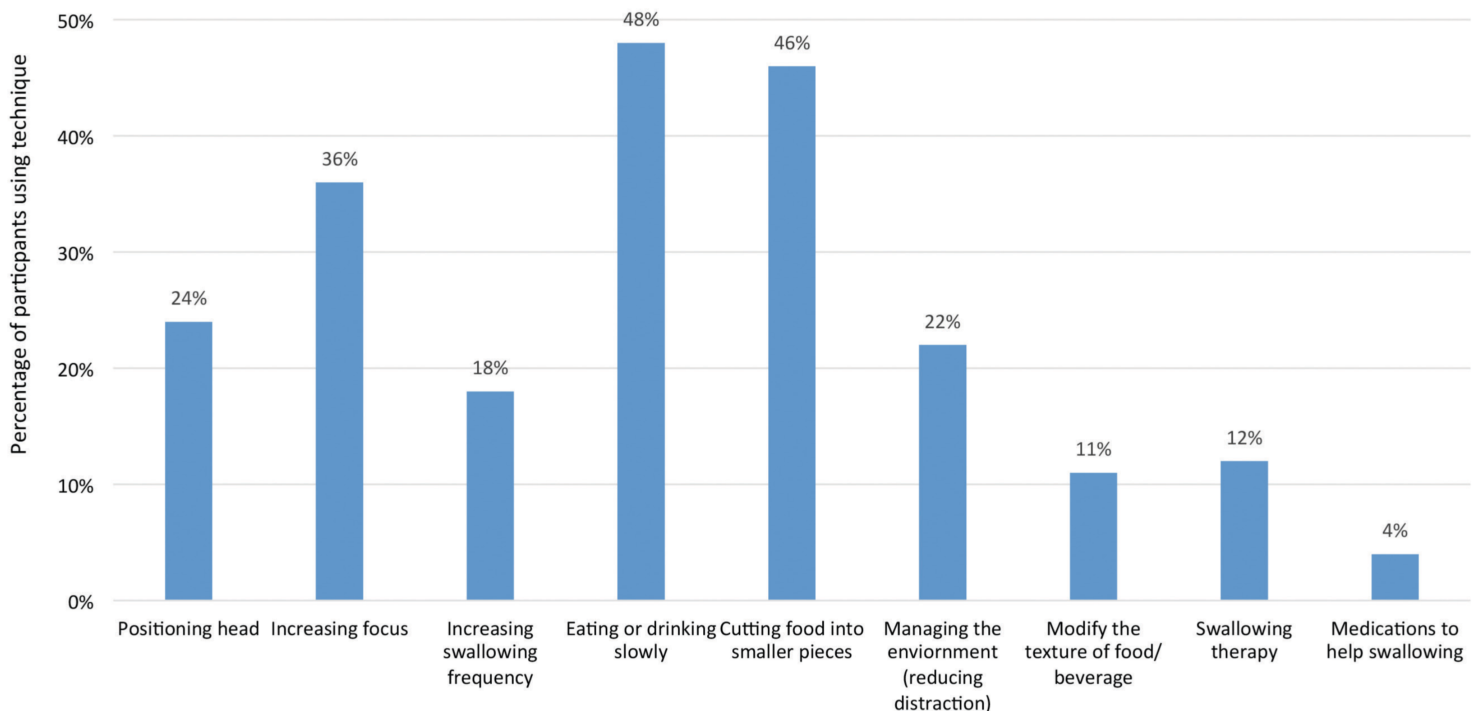
Frazier Free Water Protocol:

- The Frazier Free Water Protocol offers safety guidelines when drinking water. For example, water intake can occur up to 30 minutes prior to and after meal, but not during a meal
  - 2% have tried this method
  - 81% have not tried this method
  - 17% are not sure if they have tried this method

Techniques to manage swallowing difficulties:

- For the participants in this survey, the most frequently used techniques to improve swallowing include eating or drinking more slowly, cutting food into smaller pieces, increasing focus on swallowing habits, positioning the head to improve swallowing, and managing the environment (i.e., to reduce distraction; See Figure 3)

Figure 3. Techniques to improve swallowing (N=193)



Heimlich Maneuver (N=1,376):

- Heimlich maneuver is a first-aid procedure for dislodging an obstruction from a person's windpipe in which a sudden strong pressure is applied on the abdomen
  - 9% of participants have received the Heimlich maneuver
  - 32% reported that they have family members who have been trained in the Heimlich maneuver
  - 7% reported that care providers have been trained in the Heimlich maneuver

Modified Liquid Diet: For those on a modified liquid diet

- 7% use nectar
- 3% use honey
- 5% use pudding
- 4% use a different liquid diet ("other")

QUALITY OF LIFE:

- 75% of the participants reported good to excellent general quality of life (See Figure 4)
- 19% of the participants reported that swallowing difficulties had a moderate to extreme impact on quality of life, with 38% reporting that swallowing difficulties impacted quality of life "a little bit" (See Figure 5)

Figure 4. General quality of life

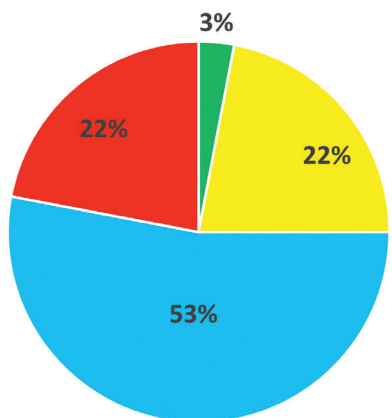
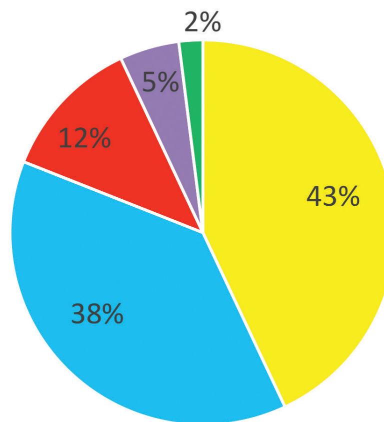


Figure 5. The impact of swallowing difficulties on quality of life



COMMENTS FROM PARTICIPANTS

Comments related to swallowing difficulties:

- "I tend to have problems swallowing my pills or thin fluids and may get a 'coughing fit' if it goes down the wrong pipe."
- "I have difficulty swallowing large pills and vitamins, but no difficulty swallowing few small pills at once or all at one time."
- "Only very large pills are problematic."
- "My biggest difficulty is swallowing the large calcium pill. If I cut it in half then the cut edges hurt my throat and leaves debris."
- "It is difficult to keep from choking when eating something crumbling or small pieces of food as cornbread or nuts and sweets…[they] seem to tickle the back of my throat, and I have a coughing fit."
- "I do have difficulty with swallowing meat and other products that are hard to cut into small pieces. Also dry foods like toast, popcorn, dry cookies or crackers. I have trouble eating sharp-tasting foods or drinks, [such as] peppermint, orange juice, pepper, spices."
- "I believe most of my swallowing and coughing episodes are due to anxiety. I go into a hysterical spasm of coughing when I am the slightest bit under pressure."
- "In addition to a bit of a problem with food residue, I also have a problem with a runny nose when eating."

- “I have trouble eating hard cheese (crumbles get stuck in my throat) and hard bread when crumbs go down wrong pipe. I start to cough for 5 minutes in between sneezing and eyes watering.”
- “A lot of the time I can’t even swallow the saliva in my mouth. It seem that my saliva is sometimes thick and I choke on it.”
- “I often seem to swallow a bubble of air when I take my pills and I can feel it in my upper chest or lower throat. Sometimes it comes up as a “burp” and so does water come up with it, that’s embarrassing and disgusting.”
- “Overall, I eat slower than I used to eat. This is not intentional. I am a speech language therapist with training in dysphagia. I am monitoring my own swallowing. Meat is not a problem unless the meat is very dry, then it is effortful to swallow, extra liquid is helpful.”
- “My biggest problem with eating or drinking is cough usually at every meal I get a coughing spell that leads to choking. When I laugh it leads to coughing. When I talk I become breathless before finishing my sentence.”
- “My main problem is swallowing saliva.”
- “I tend to have problems swallowing my pills or thin fluids and may get a “coughing fit” if it goes down the wrong pipe. The “coughing fit” is what people notice.”

Fearful moments:

- “A few times I have had food stuck in my throat for several minutes. I am afraid it is going to cut off my breathing and I will die! I keep burping slowly and as shallow as I can so it doesn’t block my throat entirely. It is blocked somewhat. Scary!”
- “Most of the time it feels like there is something caught in my throat.”
- “Sometimes I’m awakened at night with saliva entering the windpipe and causing me to wake up, sit up, and cough. I’ve not had respiratory disease as a result but it scares me.”

Anecdotes:

- “I do take somewhat smaller bites and chew a bit longer.”
- “I avoid some foods which I know I will choke on.”
- “My wife and therapists are constantly telling me that I should take smaller bites. However, I start choking with small things like just swallowing my spit.”
- “I try to eat food that I try to finish one mouthful before putting another in.”
- “A speech therapist…taught me how to swallow correctly. I try to be more focused on chewing and swallowing when eating.”

General thoughts and suggestions pertaining to many of the comments within this survey are noted below.

SUMMARY AND DISCUSSION

For individuals with Parkinson's disease (PD) swallowing difficulties are highly prevalent[4] and can lead to isolation, emotional disturbance, medical problems (i.e., respiratory infections; pneumonia), and even mortality[1]. Swallowing difficulties have been found to adversely impact quality of life[2,6,7]. This survey was designed to obtain the patient's perspective about swallowing difficulties, perspectives about intervention for swallowing difficulties, and the impact of swallowing on quality of life.

General Take Home Points:

- Self-reported swallowing difficulties were highly prevalent for the participants in this study: 67% of the participants reported that they experience swallowing difficulties, with 24% reporting moderate to severe swallowing difficulties and 43% of participants reporting mild difficulties with swallowing.
- Despite the high report of swallowing difficulties, only 34% of the participants have had a swallowing evaluation.
- 19% of the participants reported that they require some assistance with eating.
- 12% of the participants reported that they consume foods and/or beverages that they are not supposed to eat or drink, which has implications for safety (i.e., increased risk for choking and aspiration).
- 35% of the participants reported that they try to hide or minimize their swallowing difficulty, and swallowing difficulties may interfere with dining or eating with others for many participants.
  - Such findings have implications on psychological well-being (i.e., increased risk of isolation, frustration, guilt, depression, etc.)
- The most frequently reported swallowing related symptoms included difficulty chewing solid food that requires a lot of chewing, experiencing too much saliva in one's mouth when not eating, wiping ones nose when eating or drinking, sneezing while eating, and heartburn or acid reflux.

OBJECTIVE 1: To identify the relationships between age, PD duration, and severity of swallowing difficulty from the patient's perspective.

- There is greater risk for difficulties with swallowing as age and disease duration increase.
- Disease duration more so than age appears to be a better predictor for increased swallowing difficulties.
  - The **Advanced Disease Duration group (11+ years)** for **both Younger and Older participants** reported symptoms in greater frequency as compared to the **Early Disease Duration** and **Advanced 6-10 Years Disease Duration groups**, suggesting that disease duration increases the risk for swallowing difficulties for individuals with PD.

OBJECTIVE 2: To understand the patient's perspective about assessment and treatment for swallowing function.

- 34% of the participants have had a swallowing evaluation.
- 37% reported that they ask about the expertise of the clinician who is evaluating swallowing.
- The majority of the participants in this survey are unaware of common swallowing assessment procedures, and even fewer have had a swallowing assessment or discussed treatment, despite the high rate of individuals reporting swallowing difficulties.
- For the participants in this survey, the most frequently used techniques to improve swallowing include eating or drinking more slowly, cutting food into smaller pieces, increasing focus on swallowing habits, positioning the head to improve swallowing, and managing the environment (i.e., to reduce distraction).

OBJECTIVE 3: To understand the impact of swallowing on quality of life.

- 75% of the participants reported good to excellent general quality of life.
- Though, despite a high percentage of participants indicating good to excellent quality of life, 19% of the participants reported that swallowing difficulties had a moderate to extreme [negative] impact on quality of life, with 38% reporting that swallowing difficulties impacted quality of life "a little bit." Thus, addressing swallowing difficulties (via assessment and intervention) may improve quality of life.

GENERAL THOUGHTS AND RECOMMENDATIONS:

- **Swallowing difficulties are widely underdiagnosed and underestimated regarding patients' centered care[4].** Especially in early stages, the causal association between disease and swallowing disabilities remains unnoticed, which may be accounted for by the inability of caregivers and physicians to detect subtle swallowing problems and by the low self-awareness among PD patients[4].
- Given the high prevalence of swallowing difficulties for PWP identified in other research[4], the patient's perspective about swallowing difficulties as noted in this report, and risks for life-threatening consequences of swallowing difficulties (such as choking or high rates of aspiration - oftentimes silent aspiration where there is entry of a foreign object into one's airways without resulting in coughing; Simons, 2017), **increased awareness of and assessment and intervention for swallowing difficulties** for individuals with PD is needed. PWP are encouraged to speak to their doctors and treatment providers about swallowing difficulties, assessments, and treatment throughout their disease course.
    - o It is common for individuals with swallowing difficulties to be unaware of their symptoms or to minimize the swallowing difficulties. It is important for PWP to be proactive about noticing signs and symptoms of swallowing difficulties (i.e., as highlighted in PASS) and to request an evaluation/treatment by Speech Language Pathologist who specializes in swallowing.
    - o Earlier swallowing intervention with follow-up monitoring and education may have significant benefits for PWP over time.
- Standardized screening programs for swallowing difficulties as well as early intervention might be an important cornerstone in PD to maintain or even improve quality of life, prevent patients from severe health threats as long as possible, and help to significantly reduce malnutrition, aspiration pneumonia, and mortality rates[4].
- Treatment options are available, including speech therapy rehabilitation with a focus on swallowing; postural and airway protective maneuvers, food modification, neuromuscular electrical stimulation, and surgical treatments[11,12].
    - Treatment is to maintain and activate the affected abilities, therewith moderating the social isolation of these patients.
    - Compensatory maneuvers can be very effective in improving swallowing function and safety[12]: learning different approaches to eating and drinking to improve safety while eating and swallowing (i.e., meeting with a Speech Therapist who specializes in swallowing treatments for recommendations). Examples include:
        - Tucking your chin when swallowing (head positioning)
        - Taking small bites/sips
        - Swallowing twice per bite and sip
        - Refraining from talking while eating
        - Changing consistency of foods (i.e., soft cut-up foods or thickened liquids) can be helpful
        - Swallowing pills in applesauce or yogurt, cutting pills in half, or crushing pills if possible

- ▫ Consensus has not been reached to determine whether or not medications can improve swallowing difficulties[11], though some research has supported use of medications (dopaminergic treatment) as a first effort treatment to improve swallowing dysfunction[14].
- ▫ Swallowing exercises have been found to be helpful:
  - Expiratory Muscle Strength Training and Video-Assisted Swallowing Therapy have been proven to be effective for persistent symptoms of swallowing difficulties[11].
  - Exercises for the mouth and throat to assist with food/liquid propulsion, containment, clearance, and airway protection may be of help.
  - There is also research pertaining to the use of Lee Silverman's Voice Treatment (LSVT) and improving swallowing function[15,16]. Because the muscles and structures of the voice are interconnected with swallowing, some PWP have seen improvement in swallowing following training and application of LSVT.

- Given the high prevalence of swallowing dysfunction and the impact such difficulties have on feelings of isolation, emotional disturbance, and reduced quality of life, cognitive-behavioral therapy (psychotherapy) may also be a helpful treatment to assist individuals with coping with the life changes that result from swallowing difficulties[13].
- Continued research on swallowing function across age and disease duration groups and impact on well-being for PWP is needed.
- Patient reported outcomes is important. Moreover, measurement from the patient's perspective is important and needed because 1. Clinicians and patient perspectives may differ[17], 2. These measures often gauge the impact of a disease or condition in a daily living setting, 3. This information can guide management strategies[1], and 4. Patient reported experiences can validate and comfort individuals with similar experiences.

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